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*J Med Ethics* 2009 35: 733-738
doi: 10.1136/jme.2009.030783

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Best interests, dementia and the Mental Capacity Act (2005)

T Hope, A Slowther, J Eccles

ABSTRACT
The Mental Capacity Act (MCA) (2005) is an impressive piece of legislation that deserves serious ethical attention, but much of the commentary on the Act has focussed on its legal and practical implications rather than the underlying ethical concepts. This paper examines the approach that the Act takes to best interests. The Act does not provide an account of the underlying concept of best interests. Instead it lists factors that must be considered in determining best interests, and the Code of Practice to the Act states that this list is incomplete. This paper argues that this general approach is correct, contrary to some accounts of best interests. The checklist includes items that are unhelpful. Furthermore, neither the Act nor its Code of Practice provides sufficient guidance to carers faced with difficult decisions concerning best interests. This paper suggests ways in which the checklist can be developed and discusses cases that could be used in an updated Code of Practice.

“… but answer me this: can man’s interests be correctly calculated?” (Dostoevsky, p 23)

The Mental Capacity Act (MCA) (2005) is an impressive piece of legislation that deserves serious ethical attention. We will examine the approach that the Act takes to best interests. We will argue that although the general approach is right many of the details are wrong. We will propose ways in which the Code of Practice could be developed to correct the current deficiencies and to improve the ethical quality of decisions made under the Act. Our clinical focus is on people who lack capacity because of dementia.

CHOICE, HYPOTHETICAL CHOICE AND BEST INTERESTS
Discussions of medical decision-making often promote the idea of a hierarchy. According to this hierarchy we should give precedence to a person’s valid choices. If a person cannot make, and has not made, a valid choice then the decision should be made on the basis of a hypothetical choice (usually called substituted judgement). Finally, if neither of the above two approaches is possible, we should treat the person in his or her best interests. In box 1 we outline these three approaches to decision-making together with some distinctions relevant to each. We will make use of these distinctions as we discuss the approach of the MCA.

DECISION-MAKING UNDER THE MCA
With regard to adults who lack capacity the MCA makes explicit a three-step approach to decision-making:

Step 1
Enable the patient to make a valid choice at the time the decision needs to be taken if at all possible, and respect that choice.

Step 2
If the patient lacks capacity and cannot be enabled to gain capacity then follow the choice that the patient has expressed in a valid and applicable advance decision, if one exists.

Step 3
If the patient lacks capacity, and he or she cannot be enabled to gain capacity, and no valid and applicable advance decision exists (or can be found), then the patient should be treated in his or her best interests.

The MCA, in keeping with most ethical and conceptual analyses, does not view a person’s valid choice as necessarily the same as his or her best interests. A person can be mistaken, for example, about what is best for him or her; or can make a valid decision knowing that it is unlikely to be in his or her best interests.

Neither does the MCA see a valid and applicable advance decision as a component of best interests but instead as separate from and as trumping best interests (step 2). The Act states: “If P has made an advance decision which is (a) valid, and (b) applicable to a treatment, the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.”

One point to note at this stage is that the MCA condenses the three levels in the hierarchy outlined in box 1 into two levels. Priority is given to valid choice if possible and to best interests if not. Best interests under the MCA incorporates both what we have called hypothetical choice in box 1 (level 2) and what we have called best interests (level 3). In the remainder of this paper, when we refer to best interests we use the term in its legal sense. That is, best interests provide the criteria for treating a person who lacks capacity and who has not made a valid choice (through a valid and applicable advance decision).

BEST INTERESTS WITHIN THE MCA
If a person lacks capacity, and there is no valid and applicable advance decision, then, according to the MCA, the patient should normally be treated in his or her best interests (step 3).

Section 4(6) of the MCA provides a checklist of factors that must be considered “as far as is reasonably ascertainable” in determining best...
Box 1 A classification of approaches to decision-making

1. Valid choice
   (a) Contemporaneous valid choice: A choice (e.g. refusal of treatment) made about a current situation is valid if the person has capacity, is properly informed and can make the choice voluntarily and without coercion.
   (b) Prior (advance) valid and applicable choice: The person now lacks the capacity to make the choice but had previously, when he or she had capacity, made a choice that was valid (see (a) above) and that is applicable to the current circumstances.

2. Hypothetical choice (substituted judgement)
   (a) External sense: The choice that the person would have made at a time shortly before losing capacity had he or she considered the current situation. In other words, what the person would have written or said in a valid and applicable advance decision had he or she made one shortly before losing capacity.
   (b) Internal sense: What the person would now choose were he or she (magically) to regain capacity for long enough to make a valid choice.

3. Best interests
   The decision that would maximise the person's wellbeing. Wellbeing is not necessarily the same as what a person validly chooses: people may make valid choices that do not maximise their own wellbeing, for example a choice may be foolish, or it may be made to benefit another. Various accounts of wellbeing have been proposed and these have been usefully classified into three types4 (although the classification is not entirely satisfactory).
   (a) Mental state theories: Wellbeing is defined in terms of mental states. At its simplest (hedonism) it is the view that happiness or pleasure is the only intrinsic good and unhappiness or pain the only intrinsic bad. The theory can be enriched (and complicated) by allowing a greater plurality of states of mind as contributing to wellbeing, although this raises the problem of which mental states these should be.
   (b) Desire-fulfilment theories: Wellbeing consists in having one's desires fulfilled. It is plausible that to maximise a person's wellbeing we ought to give him or her what he or she wants. If desire-fulfilment theories are to provide a reasonable account of wellbeing, it is necessary to restrict the relevant set of desires. On one view only those desires pertaining to life as a whole count as relevant in the analysis of wellbeing. These are desires that relate to a person's life plan.
   (c) Objective list theories: According to these theories certain things can be good or bad for a person and can contribute to his or her wellbeing, whether or not they are desired and whether or not they lead to a "pleasurable" mental state. Examples of the kind of thing that have been given as intrinsically good in this way are engaging in deep personal relationships, rational activity and the development of one's abilities. Examples of things that are bad might include being betrayed, or deceived, or gaining pleasure from cruelty.

interests. This is organised into three subsections. It reads:

"(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity).
(b) the beliefs and values that would be likely to influence his decision if he had capacity,
(c) the other factors that he would be likely to consider if he were able to do so."
decision when the evidence on this matter is poor. This reason could be given in defence of the MCA’s silence on the underlying meaning of best interests. In our view, however, this is a weak defence. The more appropriate response to the problem of lack of evidence would be to give an account of best interests based on the external sense of substituted judgement outlined in box 1, and to present the checklist as the procedure through which to meet this objective, as best one can, even when the evidence is poor. Using the checklist procedure in order to make as good a judgement as one can about what the person would have written in an advance decision is different from using the checklist in order to judge what is in a person’s best interests, when the core meaning(s) of best interests is left to the decision-maker.

A second reason is to argue that in understanding this definition the notions of valid and applicable are so crucial that it is not helpful to base the definition (or objective) of best interests on a putative advance decision without a much more detailed understanding of these notions. This argument may be valid but highlights an important problem with the Act’s position on advance decisions: that practical decisions will depend critically on the interpretations of the notions of valid and applicable and many key problems with these interpretations are not addressed.

The third reason for rejecting a conception of best interests based on the external sense of substituted judgement is a rejection of the principle that a valid and applicable advance decision must always be determinative. This is not consistent with the MCA of course. There is a substantial literature on the strengths and weaknesses of advance decisions (Dworkin; Telø, Berghmans; Biegler et al; Widdershoven and Berghmans; Fagerlin and Schneider.) A discussion of this literature is beyond the scope of this paper. Our point is that given that the Act does give overriding authority to a valid and applicable advance decision, best interests might have been defined in terms of the hypothetical contents of such an advance decision.

The Code of Practice in explaining why best interests is not defined in the Act gives a fourth set of reasons. It states simply (section 5.5): “This is because so many different types of decisions and actions are covered by the Act, and so many different people and circumstances are affected by it.” None of these reasons, however, provides grounds for why no objective, or aim, could be stated. At most they are reasons for why operationalising the objective may be complex.

**The internal sense of substituted judgement**

Whatever one’s views about the role of advance decisions, most of those writing in this area accept the principle that an adult with capacity has the right to have a contemporaneous decision to refuse any treatment (including life-saving treatment) respected and many jurisdictions uphold it. This raises the question of whether there is an approach to best interests that can be developed from this generally accepted principle. One promising answer is to adopt the internal sense of substituted judgement. According to this view (see box 1) we ask the hypothetical question: what decision would the person make now, if he or she were “magically” able to regain capacity long enough to make a decision, but that apart from regaining capacity, he or she would remain in exactly the same situation as he or she is in currently? (see for example Buchanan and Brock; Berghmans; Savulescu and Dickenson) McCubbin and Weiszthub argue essentially in favour of the position that this type of substituted judgement (which they call pure best interests) should be the core meaning (or objective) of best interests on the grounds that it is derived from the right of an adult with capacity to have a contemporaneous decision respected.

Some people may consider the hypothetical question meaningless with its magical and counterfactual components. In our view it is not meaningless but it is fatally underspecified. Consider the following hypothetical case inspired by the account of Margo and the discussions by Dworkin and Dresser:

**Case 1: Mrs K: a person with dementia who enjoys life and now has a treatable life-threatening illness**

Mrs K has moderately severe Alzheimer’s disease, as had her mother. She cannot recognise her close relatives although she seems to enjoy their visits. She is cheerful and greets the people around her. She gives every appearance of enjoying watching TV programmes she would previously have despised although it is doubtful whether she can follow the plots. She enjoys wandering around the garden of the nursing home looking at the flowers. She enjoys cups of tea and mealtimes. Mrs K has a severe chest infection. Without treatment she is expected to deteriorate and die. With intravenous antibiotics she is likely to be cured.

Mrs K had been a university lecturer. She had always valued intellectual pursuits. She had often said to her daughter that if she ever developed Alzheimer’s disease like her mother then she would like to die.

How can we apply the internal sense of substituted judgement to the case of Mrs K? In order to do so we must ask what decision would Mrs K make if she were to regain capacity (magically). There are, however, a number of issues that would need to be clarified in trying to answer this question. For example:

1. Does Mrs K, in this magical scenario, still hold a strong value regarding intellectual pursuits? We can assume perhaps that this value no longer means anything to her now that she has dementia. So the question is, in the magical scenario in which she regains capacity to weigh up the pros and cons of antibiotic treatment, does she also regain the capacity to consider the value about intellectual pursuits? Or, even if she now lacks such values, does she remember that she once held them?

2. Does the magical scenario allow her to remember and evaluate the pleasure that she now gets from walking round the garden or from TV? And how is such evaluation to be made? Her former self would not have got pleasure from the TV programmes she now enjoys. In this magical scenario does she not only regain capacity but also her previous negative evaluation of the programmes, or does she maintain the positive attitude towards the TV programmes?

Our answers to these questions cannot be determined by looking more deeply into the concept of substituted judgement. Instead we must first decide the extent and way in which we take into account the various issues such as her previously held values and her current pleasures. In deciding what is the right thing to do when a person lacks capacity, the concept of the person’s own hypothetical choice understood in the internal sense (2b in box 1) is insufficient.

**CONCEPTS OF BEST INTERESTS BASED ON DESIRE-FULFILMENT**

Having rejected substituted judgement as a basis we turn now to various other conceptions of best interests (see box 1).

Can we perhaps salvage some of the principle of respecting capacitous choice by respecting not so much present choice, as
present desires? These are not the same, of course, but they are closely related particularly when we have someone with compromised capacity. There are two different approaches to understanding present desires: a dispositional account and a straightforward account in terms of current actual desires. Savulescu and Dickenson\textsuperscript{19} argue that a dispositional account of desires can help in considering people who lack capacity. On this account both past behaviour (and views) as well as predicted future behaviour can be evidence for present dispositions to act. Savulescu and Dickenson\textsuperscript{19} write however: “The capacity to have (dispositional) preferences is lost when the relevant disposition to act is permanently lost. The concept of a present desire based on a dispositional account collapses in situations such as dementia when a person is unlikely to regain capacity to express valid choices.”

Another approach is to give at least considerable weight to the actual current desires and choices of the person even though he or she lacks the current capacity to make a valid choice. Consider the following situation. A person with dementia has considerable cognitive impairment even lacking the linguistic ability to express choices through words. Such a person may nevertheless make choices through behaviour. The person might for example choose some foods and not others when the foods are laid out buffet style. Or the person may of his or her own volition go out into the garden and sit at what seems to be his or her favourite seat. Some of these behavioural choices may not be in his or her longer-term best interests: perhaps, for example, he or she sits in the garden on a wet day, inadequately clothed.

A person with dementia may fail tests of capacity for almost any decision and yet may have wishes and desires and be able to express these, if not verbally then behaviourally. It would be in keeping with the value of respecting capacitous choices to give at least some weight to such desires. If our concept of best interests is primarily in terms of the mental state, or the desire-fulfilment, approaches (see box 1) then one might say that there are situations when we should allow the person with dementia to do what he or she wishes or desires even though he or she lacks capacity with regard to the issue at stake. Two points should be noted. First we may not be happy to allow the person to behave in a seriously foolish or reckless manner. Should the staff stop her from doing this?

Judgements need to be made as to how much weight to give to previous values and views, and how much to current views, wishes, desires and experiences of pleasure and pain. It is implausible to solve these problems by giving dominant weight to one consideration only. The relative weight that we should put on each consideration depends, we believe, on various details of the situation and no general answer can be given as to what should take precedence (see Holm).\textsuperscript{19} Consider the following hypothetical cases:

Case 2: Macho man gets Alzheimer’s disease
Mr L prides himself on his machismo. He plays dangerous sports. He considers people who are worried about danger, or pain, as wimps. When he goes to the dentist he refuses any analgesia. He prides himself on being able to withstand pain. Mr L would not want any analgesia for pain relief even if he had dementia. Mr L has Alzheimer’s disease. He develops dental caries for which treatment is straightforward but involves drilling that without analgesia would be very painful. Without dental work the teeth will rapidly deteriorate and will then cause Mr L a great deal of pain as well as preventing him from eating. The dentist tries to respect Mr L’s previous values but every time he starts drilling near the nerve endings Mr L screams with pain. The dentist has an apparatus that would hold Mr L’s head and jaw secure to allow him carry out the work without analgesia. The dentist, not surprisingly, is reluctant to do this.

This case, developed from remarks by Dresser\textsuperscript{18} and Kuhse\textsuperscript{14} and on a case in Hope,\textsuperscript{25} challenges the view that previous values (or critical interests)\textsuperscript{17} should always be respected. But previous values do have some weight:

Case 3(a): Religious objection to eating pork
Mrs M has been, for most of her life, a member of a religious group that does not eat pork. Mrs M develops Alzheimer’s disease and lives in a nursing home. For breakfast many of the residents have an English breakfast consisting of bacon and eggs. The staff, knowing of Mrs M’s previous religious views, do not give her bacon. Mrs M is attracted by the smell of cooking bacon. One day, before the staff can stop her Mrs M takes a piece of bacon from the plate of another resident and eats it with obvious relish. After this she tries to take bacon from residents’ plates each breakfast.

Should the staff stop her from doing this? and now consider this further development:

Case 3(b)
Mrs M has taken a piece of bacon from another resident’s plate. She is just putting it into her mouth when a member of staff who is standing nearby notices. This member of staff quickly grabs Mrs M’s arm, forces her mouth open and removes the piece of bacon before Mrs M can swallow it.

Was this the right thing to do? and, finally, what should Mr N’s daughter do in the following situation?:

Case 4: The vegetarian with dementia
Mr N has been a committed vegetarian for most of his adult life. He develops Alzheimer’s disease. He lives with his daughter who is not vegetarian. She provides him with vegetarian food, but it
becomes clear that Mr N is raiding her fridge and eating the processed meats and when his daughter catches him eating meat he is doing so with obvious pleasure.

It does seem right to try and enable a person, who on religious or moral grounds objects to eating meat, to continue to abstain even when he or she no longer has the understanding or control. It is right to provide alternative food to such a person and to take straightforward measures to prevent him or her from eating meat once he or she has dementia. However, snatching the food out of the mouth, an action that will be experienced as an unprovoked and senseless physical assault, seems to us to be going too far. The person’s current experiences and current understanding make a difference, and may provide sufficient grounds for overriding respect for previous values (or decisions).

This series of cases demonstrates, we believe, that the relative weights to be given to previous values and current interests depend on several factors. These include: what would need to be done in order to respect previous values; the strength of those previous values; the effect of respect for previous values on the person’s current wellbeing (for example on current mental state—see box 1) and current wishes and desires. One issue that these case examples raise is whether the nature of the previous views is in itself relevant to the question of how much weight they are given.

Compare Mr N (case 4 above) with Mrs K (case 1). Mr N had a moral objection to eating meat. He believed, let us suppose, that the killing of animals for food is a serious moral wrong. He believed it was wrong not only for himself but also for others. Had he discussed the scenario in case 4 at a time when he still had capacity he would have said that for the sake of the animals, he would want to be prevented from eating meat.

Mrs K’s values regarding intellectual activities are not primarily moral values. If, when she has dementia she watches TV soaps and enjoys them, she would not, according to her previous views, be harming anyone or anything. It is simply that she does not wish to be the kind of person who enjoys these pursuits. Should we give more weight to respecting Mr N’s vegetarianism than Mrs K’s values on the grounds that Mr N’s views are moral in nature? We can find no good grounds on the basis of best interests for giving more weight to the previous views of a person purely because those views are moral views.

The strength of those previous views and the degree of importance to the person of respecting them is relevant. Perhaps on the whole most of us would feel more strongly that our moral views should be respected even if we no longer understand them, than that our aesthetic views are respected. However, it is the strength rather than the nature of the previous views that is, we believe, the key point.

DEVELOPING THE CHECKLIST FOR BEST INTERESTS IN THE MCA CODE OF PRACTICE

Subsections (b) and (c) of the MCA best interests checklist (see above) suggest that in deciding about best interests we should consider what hypothetical choice (substituted judgement), in the internal sense (see box 1), the person might make. The Code of Practice supports this suggestion (eg, section 5.18): “When trying to work out someone’s best interests, the decision-maker should try to identify all the issues that would be most relevant to the individual who lacks capacity and to the particular decision, as well as those in the ‘checklist’”. These two subsections, and the Code of Practice statement have the problems in interpreting hypothetical choice that we have discussed above. We have argued that the key ethical decisions need to be made before we can apply the test of hypothetical choice because there is no a priori answer to the question of what state we imagine the person to be in “if he had capacity”, or “if he were able to do so”, or “would be most relevant to the individual”.

It is therefore only subsection (a), “the person’s past and present wishes and feelings” that provides, in our view, any valuable guidance in judging the best interests of a person who lacks capacity. The Code of Practice, however, usefully emphasises that the approach to gaining evidence about best interests should be as comprehensive as is reasonable, for example in stressing the need to consider all circumstances that might be relevant (eg, section 5.13) and the need to consult widely (eg, sections 5.49 and 5.53).

The Code of Practice makes it clear that the best interests’ checklist is incomplete. This provides an opportunity for developing the Code of Practice to expand the checklist beyond what it states in sections 5.46 and 5.47 (see above) and provide guidance for practitioners with regard to the ambiguities inherent in the wording of the Act.

On the basis of the arguments presented in this paper, we propose the following expanded checklist as both more complete and as providing more clarity than the current list.
1. The person’s wishes when he or she had capacity.
2. The person’s values when he or she had capacity.
3. The strength with which he or she held these wishes and values.
4. His or her current wishes.
5. His or her current values, including current lack of understanding or awareness of previous values.
6. The strength with which he or she holds these wishes and values.
7. The person’s current, and likely future, experiences (eg, of pleasure and pain).
8. The nature of what we have to do in order to follow the previous wishes and the likely impact of that on the person’s current and future experiences (see cases 3(a) and 3(b) above).

Finally,
9. In making the judgement as to how much weight to give each of these considerations it is important to take account of the degree of evidence for each consideration. As the Code of Practice makes clear (section 5.40) relevant evidence includes current behaviour and expressions of pleasure as well as evidence about past wishes and values.

The Code of Practice could use case examples such as that of Mrs K (case 1 above) to show how different factors of the checklist might be used and weighted in coming to a judgement.

CONCLUSION

The approach to best interests in the MCA is flawed in three ways. First, subsections (b) and (c) of the MCA’s checklist of best interests ask the decision-maker to use the idea of the internal sense of hypothetical choice (substituted judgement). Such hypothetical choice, we have argued, cannot help the decision-maker because the key judgements must be made in order to specify the conditions under which the choice is
imagined. Subsections (b) and (c) thus add nothing of value to subsection (a). Second, the best interests’ checklist is incomplete and provides rather little guidance for the decision-maker. Third, the conceptual relationships between the position the Act takes on advance decisions and on best interests are inadequately clarified.

The first flaw is relatively benign although if subsections (b) and (c) are invoked it can mask what assumptions are being made in deciding best interests. The second can be addressed through developing the Code of Practice. We have suggested ways in which the checklist can be expanded, and cases that could be used for showing how it should be applied. With regard to the third issue, we have argued that the position that the Act takes with regard to advance decisions should impact on the concept of best interests within the Act. The practical effect of such impact, however, will remain slight until there is more clarity about how to decide when an advance decision is valid and applicable.

Competing interests: None.

Provenance and peer review: Not commissioned; externally peer reviewed.

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